



tourette syndrome association, inc.

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June 21, 2001

The Honorable John D. Dingell, Ranking Member
House Energy and Commerce Committee
U.S. House of Representatives
Washington, D.C. 20515

Dear Congressman Dingell:

The Tourette Syndrome Association, Inc., applauds your efforts to ensure passage of the *Bipartisan Patient Protection Act of 2001*. This legislation must be enacted by Congress to guarantee that all Americans have access to timely and appropriate medical care.

Incorporated in 1972, TSA is a national association with chapters in all fifty states. Tourette Syndrome (TS) is an inherited neurobiological disorder that affects children in all racial and ethnic groups. The symptoms of TS are rapid, repeated, and involuntary movements and sounds that are called tics. Approximately 275,000 Americans have full-blown TS and many more exhibit some associated symptoms or behaviors. There is no cure for TS although some individuals benefit from medication. We actively support programs developed to inform the general public as well as the medical and educational communities about this neurological disorder. Moreover, each year we provide direct funding to scientists doing research on this condition.

There are approximately 25 million men, women and children in the United States suffering with rare disorders, many of whom are denied access to quality healthcare coverage because managed care organizations may deny benefits due to low demand, unfamiliarity with standards of care for unusual diagnoses, and/or the high cost of care. When benefits are denied and there is no appeals process, patients continue to suffer unnecessarily because there are no safeguards to insure the fair unbiased resolution of appeals. Continuity of care and access to clinical trials is also of significant importance to those suffering with the 6,000 known rare "orphan" diseases.

On behalf of the Tourette Syndrome Association, we wholeheartedly endorse your efforts to enact the *Bipartisan Patient Protection Act of 2001*.

Sincerely,

Judit Ungar
Executive Director

/plh

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